



# EVALBRIEF: SYSTEMS OF CARE

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## A System-level Assessment of Family and Youth Involvement by Program Development Years for Communities Funded in 1997–2000

System development in mental health care involves collaboration at the Federal, State, and local levels. Changes made at the system level can affect the ease with which children and families find their way through the service delivery system, and ultimately affect how well they improve. This *EvalBrief* examines the extent of family and youth involvement across program development years for those communities funded from 1997 to 2000. The data from all funding cohorts were collapsed into program development program years so that the trend of progress across the grant-funding cycle could be illustrated on a year-to-year basis according to the communities' ages in the grant-funded program. The results include qualitative findings, system-of-care assessment ratings, and percentage breakdowns of participation by families and youth in varied communities. This study offers a unique perspective by examining the gradual integration of families and youth within the infrastructure and governance of grantee communities.

An average rating is calculated from multiple respondents within each system-of-care community. System-of-care assessment ratings range from 1 to 5, indicating degrees of effectiveness in integrating youth and families within service delivery. A rating of 1 = no efforts have been made in this area; 2 = efforts made are in the early stage of development and have been minimally effective; 3 = efforts made are in developmental stages and moderately effective; 4 = efforts made in this area have been effective, but not sufficient; 5 = efforts made in this area have been effective and sufficient and the intended goals have been met.

### Study Highlights

- ▶ *Family and youth involvement were assessed by program development years to examine year-to-year progress. In general, the trends indicate improvement across development years.*
- ▶ *Almost all communities had family member participants on their system-of-care governing boards through program development years, although a slight decline is evident by the sixth year of funding.*
- ▶ *Communities were most successful in involving families in the service planning process and least successful in involving families in the case review process.*
- ▶ *Youth involvement in the case review process improved across development years, although fully involving youth in this particular process continues to be a challenge for system-of-care communities.*
- ▶ *Youth involvement in service planning saw a general trend toward improvement across program development years.*

### Family Involvement

A basic principle that guides systems of care and that is expressed as one of the goals of the Comprehensive

Community Mental Health Services for Children and Their Families Program, is that families should be involved in all aspects of the system of care. Systems that work well include families as partners in developing policies, making decisions, managing program operations, monitoring the quality of the program and its ability to meet the needs of the consumers, and planning and providing services. These systems provide families with the necessary supports to successfully engage in these activities.

Some of the activities in which families typically were involved at the infrastructure level were reported by various respondents during system-of-care assessment site visits. Families were involved in *policy and program oversight* activities (e.g., serving on governing boards, participating in strategic planning and budgetary decisions); *management and operations activities* (e.g., training, recruiting, attending management meetings and serving as staff); and *quality monitoring activities* (e.g., collecting data and participating in evaluation committees). Despite involvement in these activities, communities reported also that they experienced some challenges in increasing family involvement in system infrastructure activities. For example, starting or establishing a firm relationship with a family support and advocacy organization and having an adequate number of family members available to serve on governing boards or to provide direct services to other families were reported as challenges.

## Family Involvement in Governance Across Program Development Years

Through 6 years of program development, almost all communities (about 97% at the highest point) had family member participants on their system-of-care governing boards. Specifically, improvement is seen from years 2 to 4 (year 2: 87.9%; year 3: 95%; year 4: 97.1%). A slight decline is evident by the fifth (87.5%) and sixth (81.5%) years of funding. System-of-care communities that may or may not include consumer families on their governing board include American Indian and Alaska Native communities, which are governed by tribal councils or boards of directors comprised of elected members from their communities.

<sup>1</sup> *n* represents the number of communities with system-of-care assessment ratings for each program development year. The information presented in Figure 1 illustrates patterns of success and is not amenable to aggregate statistical analyses because the periodicity of assessments varies among the different groups of system-of-care communities, which results in inconsistent data that are available in any given program development year.

The percentage of governing body membership comprised of family representatives remained steady across the years, with the percent of families on the governing body ranging from about 16% to 21%. It is rare for family consumers to be active participants on governing bodies even when the system of care provides facilitating mechanisms such as evening meetings, child care, meals, or transportation. One probable explanation is that the often demanding needs of caring for a child with serious emotional disturbance and other family considerations make it difficult for parents and caregivers to assume additional duties and obligations related to governing a system of care. Given this, the relatively small percentage of family membership on governing bodies is evident.

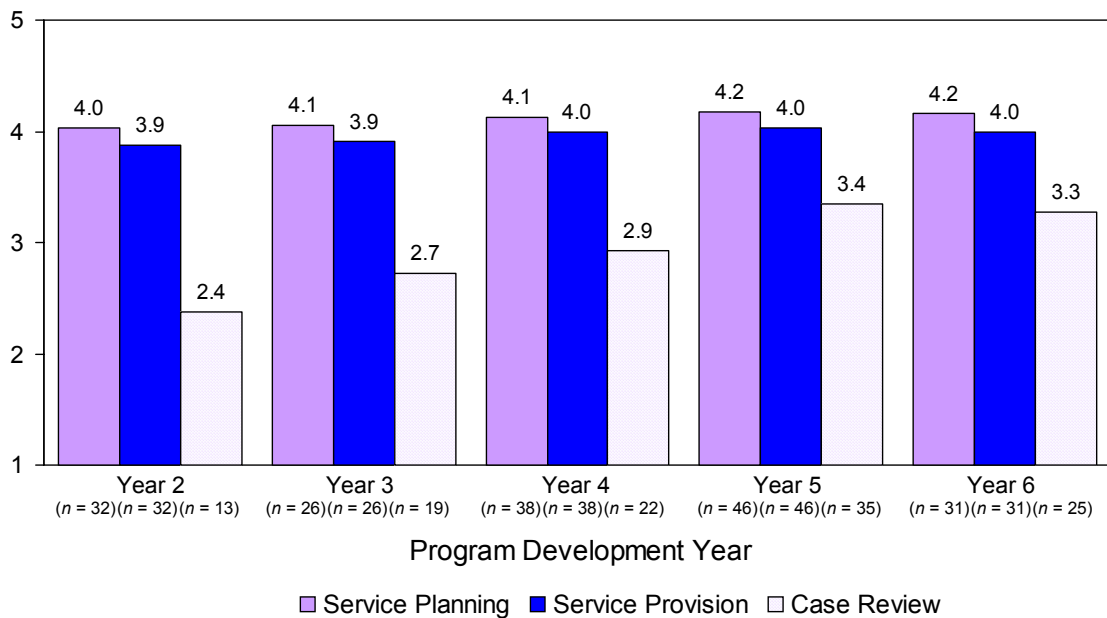
The size of governing bodies varies by community, ranging from 10 to as many as 30 or more participants. While some governing bodies have bylaws that specify the proportion of family member participants to be as much as 51%, it is more common for the family voice to be represented by a few key persons such as the director of the family advocacy organization or a lead parent who serves as staff in the program.

## Family Involvement in Service Delivery Across Program Development Years

Systems of care involved families in service delivery by engaging them as full partners in developing the service plans for their children and their families, by including them in the service delivery process, and by including them as participants when their child's care was being reviewed to meet special service needs. Figure 1<sup>1</sup> indicates that communities

- ▶ were *most* successful in involving families in the service planning process and *least* successful in involving families in the case review process,
- ▶ improved over time in involving families in the service planning process and in including them in service provision activities, and
- ▶ made the most dramatic improvement in involving families in the case review process

**Figure 1**  
**Level of Family Involvement in Service Planning, Service Provision, and Case Review by Program Development Year**



where planning was conducted to meet special service needs of their children.

## Youth Involvement

Involving youth in decision-making has become increasingly important in systems of care. The national evaluation began collecting information about youth involvement during a pilot study conducted in 2005 as part of the system-of-care

assessment that examined youth involvement in all aspects of their local systems of care. A series of five focus groups consisting of a total of 22 youth and 11 youth coordinators was conducted, and additional youth and youth coordinators were interviewed individually in five communities. Preliminary findings from this pilot study indicated that in some system-of-care communities,

- infrastructure was being developed to support the development and implementation of youth

**Table 1**  
**Average Ratings of Youth Involvement in Service Planning and Case Review by Program Development Year as Reported by Case Review Committee Members, Caregivers, and Care Coordinators**

|  | Year 2                     | Year 3                     | Year 4                      | Year 5                      | Year 6                     |
|--|----------------------------|----------------------------|-----------------------------|-----------------------------|----------------------------|
| <b>Average Ratings of Youth Involvement as Reported by Case Review Committee Members</b> | 1.60<br>[1.23]<br>(n = 20) | 2.05<br>[1.43]<br>(n = 31) | 2.37<br>[1.55]<br>(n = 42)  | 2.38<br>[1.66]<br>(n = 63)  | 2.46<br>[1.55]<br>(n = 34) |
| <b>Average Ratings of Youth Involvement as Reported by Caregivers</b>                    | 3.36<br>[1.40]<br>(n = 77) | 4.02<br>[1.16]<br>(n = 44) | 3.76<br>[1.47]<br>(n = 82)  | 3.82<br>[1.37]<br>(n = 83)  | 3.90<br>[1.25]<br>(n = 53) |
| <b>Average Ratings of Youth Involvement as Reported by Care Coordinators</b>             | 3.95<br>[.86]<br>(n = 86)  | 4.11<br>[.96]<br>(n = 65)  | 4.07<br>[1.09]<br>(n = 112) | 4.20<br>[1.02]<br>(n = 126) | 4.19<br>[1.13]<br>(n = 67) |

Note: Average ratings presented with standard deviations in brackets. Average ratings range from 1 to 5, with 5 indicating that efforts made are effective and sufficient.

groups as a mechanism to provide peer and staff support,

- ▶ mechanisms were being developed for youth to participate in and organize activities with other youth,
- ▶ youth were being involved in decision-making activities at the governance level as well as in conducting training or providing direct services, and
- ▶ youth were being involved in the development and implementation of their own service plans and treatment.

### Youth Involvement in Service Delivery Across Program Development Years

The system-of-care assessment examined the extent to which youth were involved in service delivery activities from the perspectives of their parents or other caregivers, care coordinators, and members of case review committees. According to these groups of respondents, system-of-care communities made the following improvements (see Table 1, previous page):

- ▶ Youth involvement in the case review process improved across development years, although fully involving youth in this particular process continues to be a challenge for system-of-care communities.
- ▶ Youth involvement in service planning saw a general trend toward improvement across program development years.
- ▶ Care coordinators reported more favorably than did caregivers about youth involvement in their own service planning.

## Summary

Systems of care have made progress toward involving families and youth in the development of their programs. Although there is a relatively low percentage of family members on governing bodies, communities are increasingly including family members on their governing bodies across program development years. Communities also demonstrated improvements in involving families in service planning and provision. Care coordinators, caregivers, and case review committee members also indicate that children and youth are involved in their own service planning processes. Relatively high ratings obtained from care coordinators and caregivers indicate that children and youth almost always give input prior to service planning team meetings. In addition, those of appropriate age and ability actually attend meetings and participate in developing their goals and choosing their service options, although they are limited in final decision-making by parental concerns, permissions, mandated or court-ordered services, and other factors over which they have no control.

Study results indicate that there is a substantial improvement across program development years for both family and youth involvement in service planning. This finding conforms to the system-of-care principles emphasizing the importance of increasing family and youth involvement within the service planning and provision process. This *EvalBrief* provides insight into ways that families and youth can successfully engage as partners within their grantee communities.

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